

UTAH NEWBORN HEARING SCREENING ADVISORY COMMITTEE

**Next Meeting
August 14, 2012**

May 8, 2012, meeting minutes

In attendance: Krysta Behring, Susie Bohning, Kelly Dick, Susan Fox, Charlene Frail-McGeever, Rich Harward, Nita Jensen, Stephanie McVicar, Karen Munoz, Albert Park, Taunya Paxton, Kurt Randall, Lori Ruth- USDB, guest, Sharon Strong, Karl White, Sylvia White, Nancy Whiting- USDB, guest, Shannon Wnek

Absent –Nancy Hohler, Harper Randall, Jill Vicory, Vanya Tanner, Kathleen Pitcher-Tobey

WELCOME

Dr. Kelly Dick opened the meeting at 9:10. Members as listed above were excused from today's meeting. A motion to approve the February minutes was requested. The motion carried with all in favor and with no one abstaining.

UTAH EHDI UPDATES

Dr. Richard Harward is happy to announce that we have a new EHDI chapter Champion: Dr. Katie Jolma. Dr. Jolma is a developmental pediatrician who has recently taken over the private practice of Tom Metcalf and has done previous clinic work here at CSHCN. Dr. Jolma is the wife of Dr. Paul Carbone, who is also a pediatrician and was a pre-session presenter at the EHDI Conference held in March in St. Louis. Dr. Carbone is an authority on autism and hearing loss. Dr. Jolma and Dr. Carbone also have a son with special health care needs. Dr. Jolma is a great pediatrician who understands disabilities and will be a great chapter champion.

Dr. Harward has invited Suzanne Smith, a midwife who participates in our Homebirth Hearing Project, to join this committee. He is waiting for a response from her. One of Utah's EHDI projects has been to get midwives involved with newborn hearing screenings. ADDENDUM: Suzanne Smith accepted the invitation to sit on this Committee.

Dr. Stephanie McVicar and Kurt Randall discussed the Utah TeleAudiology pilot project. The ABR and video equipment has all been received (purchased with HRSA carryover money) and a trial run with Daniel Ladner, the technical assistant from NCHAM has been completed. Michele Thompson, a midwife in Mt. Pleasant, will be trained to prepare the cameras and equipment at the patient site, and place the electrodes on an unsedated infant. The audiologist(s) will be at our SLC office and will be able to see the test site through the camera and remotely control the ABR equipment to do the testing. The family will also be able to see the audiologist through the camera set up on their end. Ms. Thompson has 10 babies to deliver in the next few months and plans to test all of them through the teleaudiology pilot. (ADDENDUM: this project has been postponed a few weeks due to the pertussis outbreak in Sanpete County. We hope to begin the Project in July 2012). Dr. Karl White thinks this is incredible. Our State EHDI audiologists have been invited to be part of a learning community with NCHAM and other states to discuss teleaudiology. People all over the country have been talking about teleaudiology, but no one has really done it. Audiologists have done consultations this way, but our goal is to have a trained person in a remote area who is not an audiologist administer the ABR. Wisconsin has tried, but had issues with billing. There is also a group in Canada that has tried unsuccessfully. Susan Fox asked about privacy issues regarding the use of online video. Daniel will be helping with this. We will not be using a basic program; it will use a secure VPM line and meet HIPPA codes. Dr. Dick mentioned a recent presentation by James Hall, and some others in Boston, that seemed to take teleaudiology a step further by going to Tahiti and the Pacific Islands, in a very remote manner over secure VPM lines and training people on-

site (Guam). Again, Dr. White believes most of this is mainly talk about concepts; actually delivering services to 10 babies would be moving teleaudiology to a new level. A few years ago NCHAM asked states who would be interested in doing teleaudiology and 25 answered that they were already doing it. Diane Behl has been calling these states to find out what they are actually doing and has only found the Marshall Clinic in Wisconsin and Thunder Bay to be doing teleaudiology. There have only been 2 babies screened through teleaudiology in Guam. They have shown that it does work, but reimbursement has been part of the issue. Part of the advantage we have, as a state entity, is that we can screen children ages 0-3 and bill third-party coverage only, without billing the parent. The pilot concept will provide a stipend to the trained person at the remote site, and bill insurances for the audiologist's services. We will complete the pilot project, evaluate the process, and effectiveness, and then make plans to expand to additional sites. The next planned pilot location is the Uintah Basin area. We hope ABR teleaudiology will fill a "service gap" in areas of Utah without diagnostic services. Infants not passing a second screening now may languish without diagnostics because they don't have access to services. This should help get them diagnosed and referred to EI/ PIP earlier. It is very exciting to have a midwife participate. The group in eastern North Carolina has used an audiologist on each end of an evaluation. Our concept is to have an audiologist on one end with a trained lay person on the other end. The pilot won't necessarily be serving infants who have failed two screenings, but it will (hopefully) successfully prove the ABR teleaudiology service concept. Kurt noted that this is a midwife who will try to assure that ten infants are scheduled/completed to meet the goal. Dr. Karen Munoz asked if it will be a full battery including tympanometry and OAEs. Currently it will only be the ABR as it gets expensive to purchase the additional equipment to leave at the test site. We will also have to establish who has the VPN line (the audiologist or the midwife). The manufacturer of the ABR machines doesn't put security software onto the computer as it conflicts with the ABR software, but they assured Kurt that there will be no security violations in doing this remote process. Dr. White suggested getting pictures of the process and drafting a write-up for the *ASHA Leader*.

Regional hospital coordinator meetings were held in March/April in Cedar City, Provo, Salt Lake and Ogden. Dr. Shannon Wnek, Nita Jensen, and Krysta Badger led these meetings while Kurt was in Africa. Site visits were also held at Blue Mountain Hospital, San Juan Medical Center, Moab Regional Hospital, and Castlevlew Hospital. Thirteen site visits have been completed during the current grant year. Weekly hospital Hi-Track data transfers (increased from monthly transfers) were introduced and widely accepted. Hospitals that already submit data on time with monthly data deadlines have continued to be on time (85% are submitted on time), while those who are generally late are still late. The issue here is getting all of the data cleaned before the reports are run since Nita is now receiving data every day. This will resolve providers having to wait so long for results; Sylvia White is very happy about this, as she receives infant referrals to early intervention and needs documented hearing results. Nita also has a list of hospitals that are ready to use Web Hi-Track when State IT has assured that all newly required server security and encryption is in place. Dr. Harward mentioned the recent data breach of Utah Department of Health's Medicaid server administered through the State DTS office.

At the last committee meeting, Eric Smith was here to discuss a hearing aid bill for children. Dr. Harward has not heard back from Eric since this meeting. Nita researched the progress made on the bill and found that it was returned to the rules committee without review and then it was tabled. Dr. Harward and Dr. White believe this year was probably a 'teaser' to alert constituents of the plan and a proposed bill will have more traction next year. The key for next year will be to meet with the fiscal analyst earlier in order to get a better fiscal analysis. Karl will follow up with Eric; now is the time to start on that.

NATIONAL EHDI

The National EHDI conference was held in St. Louis on March 4-6, 2012. This was the largest meeting they have had with almost 1000 people in attendance, and 500 attending the pre-sessions. Evaluations are posted on

the NCHAM website (<http://ehdiconference.org/2012/includes/Evaluations2012.pdf>). Dr. Carbone's session was very highly rated. Next year's conference will be April 14-16 in Phoenix, AZ. Information is available at: <http://ehdiconference.org/>.

The annual Investing in Family Support Conference will not be held this year due to federal budget cuts. NCHAM will, however, be holding 90 minute webinars on similar topics starting in July and once a month throughout the year. This will be available on the NCHAM website and through the mailing list.

UTAH NEWBORN HEARING SCREENING STANDARDS/CEO REPORT CARDS

At the last committee meeting, it was suggested to review last year's program summaries to see what actions hospitals are taking in referring babies for outpatient testing. Kurt looked at a random selection of urban, rural, and frontier hospitals (see handout). All but the frontier locations addressed the issue of making appointments with the family to bring the baby back to the hospital for an outpatient rescreen.

Also in your packet is a draft of the CEO Hospital Report Card/Efficiency Report. Please review and give suggestions. This report will be sent to hospital CEOs and Screening Coordinators. Dr. White would like the terminology of "initial hearing screening" and "advanced screening" to be changed. He does not want this to be misinterpreted (in the 30 seconds someone might look at it) as some type of "super-duper screen" as opposed to the NICU screen that it is. It might make more sense to say "Initial Well Baby Hearing Screening" and "Initial NICU Screening"/"In-Hospital Screening". Dr. White likes the graphs comparing each hospital with the state average. Dr. Susie Bohning would like to know if other states who have implemented this (TN, NM, AZ) have shown it to be effective. Susan Fox receives the metabolic report card and knows that it has made a dramatic improvement in missing data and bad specimens. The verbal report from Arizona is that it is helpful because it keeps everyone involved up to date. Dr. Karen Munoz noted that when something is in writing, people tend to take more notice. Dr. White thinks it is a great idea and that they should be sent out quarterly. (The metabolic report goes out once a month.) The intent of the hospital is to do what is right and what is best for the patient, so it is very helpful to get the feedback and, for newborn bloodspot, they know that they will be fined if they are not up to standard. Kurt has written letters to hospital CEOs in regards to getting an audiologist on board for newborn hearing screening, etc. and they have always been quick to get it done. Dr. Harward suggested including an introduction letter to the CEO, along with the report card. There should also be a rule defining the consequences of a hospital being out of compliance for a certain length of time. Dr. White questioned who the responsible party is for the diagnostic screening, as this report clearly shows the hospital as the responsible party. Kurt believes that it is the hospital's responsibility to follow the child through diagnostics and Dr. Harward would like that ownership to remain with the hospital as well. Dr. Bohning noted that it is different with transfer babies, as once they transfer to another hospital, the receiving hospital is responsible. Most of our reports are done with the date of birth and birth site, not the screening site. So, if the hospital screening program puts in the results for PCMC it isn't always entered correctly. Getting children to the diagnostic stage is the most important and that is where we are losing kids. Dr. White would like to play the "devil's advocate" for a moment: if I were a CEO and saw that our diagnostic numbers looked bad, I would go to the audiologist and ask what he/she was going to do about it. Most likely, the audiologist would say that they have no control, that they refer the parents and then it is up to the parent to find an audiologist (if there is not one in-house), or even if they do make a specific referral, parents can choose to go wherever they want. The hospital audiologist makes recommendations, but cannot make parent's decisions. Dr. Harward thinks that with training and screening education we can still get those diagnostic numbers higher, even without in-house audiology. We do not want to remove the diagnostic portion of the report because we don't want people to think everything is fine because their screening numbers are ok. We would like to pilot this CEO report card and see how it goes. Dr. White is supportive of this. Charlene Frail-McGeever suggested including some type of education or training resources with the report card that could be used as an outreach and education tool. From a parent's perspective on

diagnostics, most parents won't go outside for an audiologist because they don't know that is an option. The law says that there has to be an audiologist on board with each hospital in some fashion and as long as the hospital is tracking the baby that audiologist has to be involved in the loop. While that audiologist is not required to do the diagnostic, they are required to see that it gets done according to protocol. Nita noted that we do still have some documentation issues, with numerous kids having been seen, but not always reported. This requires other conversations with those receiving the referral. If that CEO calls the nursery manager who says that they really are doing better than what is reported, it could be motivation in terms of reporting as well.

New audiology standards were emailed to the committee for review. Kurt facilitated a discussion on each item. Line two is ok to strike "At least 95% pass initial screening". We do not want to provide motivation to test multiple times (just to get a pass) before discharge. Line three, "At least 90%..." we do not know the national average, as this is not reported consistently but, we should have a goal that is not out of reach. At one time it was about 70%, so if we can get it to 90% that would be impressive. Karl would like to see it be 98%, but he would also like it to be realistic. Leave this line at "90%", but replace "by" with "before" to make NCHAM happy. Line four, "95% of all diagnostics..." considering that we are less than 35%, Rich would like to change this to 90%, Karl agrees. Line five, change "must" to "should". Nita noted that some hospitals are doing OAE and AABR, but only one may be reported if the results need to be entered by hand. Susie understands this to be a minimum standard. The child should receive an OAE and an AABR if it is a NICU baby. The 6th line has no edits. Line seven should be changed to "facility submits Hi-Track data weekly". Dr. Munoz thought that federal law required referral to EI sooner than 2 weeks. Dr. Bohning is afraid her report card will look bad because of the NICU babies. Charlene doesn't think that it will be a bad thing because it will get people to notice it. With no further discussion, proposal to vote on, edit, and publish based on comments. Vote to alter minimum standards, unanimously in favor, we will adopt these standards. Kurt will distribute the edited document to birthing facilities and this committee by June 1, 2012. By releasing this document we will be saying that these changes have been adopted by this committee.

RISK FACTORS FOR HEARING LOSS

As part of our regional meetings, Dr. Wnek presented on risk factors for hearing loss (as presented at the National EHDI Conference). She would like to open discussion as to what we, as a state, should do in regards to tracking babies with risk factors for hearing loss. Because of this presentation, hospitals are starting to ask what we would like them to do for tracking and reporting.

Idaho has risk indicators classified with follow-up based on the risk factor classification. This project took a lot of education with medical homes and hospitals. In 2007, before doing education, they had 270 referrals for risk factors, this jumped to 1000 referrals every year after the education outreach. Dr. Wnek does not have the number of how many of these children were identified with a hearing loss. The referring hospitals that participated in this study used a sheet at the hospital that screeners marked each risk factor and whether the child needed to be referred. This was given to the family, physician, etc. Then, Idaho State EHDI sent out a letter stating the risk factor and the need for follow-up. They also sent information to the diagnostic facility who, in turn, would contact each family to schedule an appointment. For Utah, we are thinking about looking at risk factors, but Dr. Harward has not seen any research showing that more than about 50% of the kids with hearing loss do not have risk factors. Dr. White noted that 98% of children with risk factors do not have hearing loss. We don't want to create extra work, but we do need to discuss what will fulfill our goals. Per Dr. White, in light of 50% of children with hearing loss having no risk factor, and 98% of children with risk factors having no hearing loss, we are already doing a universal program. How many more children would we really be picking up, or should we put that time and expense into tracking and follow-up. If you can imagine how much better our follow-up would be to make phone calls, etc., that would be a quantum difference. We need to worry about putting effort into tracking risk factors when it comes to CMV or meningitis. Dr. Harward would like to look at

this more specifically for things that might get missed like CMV screening and target specific areas. Nita noted that we do have a few hospital coordinators who expressed interest in being on a task force if risk factors will be tracked statewide. This would be good for a PDSA cycle. We could take one large hospital, have them track risk factors for a year and see what their success was getting those kids with risk factors to come back to test, and record how many babies they did find to have a hearing loss. If we used Utah Valley Regional Medical Center with 4000 babies, we could see how much money and time was spent and how many children were found with a hearing loss. There is no data like that in the country, so Dr. White suggested doing it in a targeted way with someone who is interested. Dr. Lara Waite, at McKay Dee Hospital, would be interested in piloting this type of project. Sylvia asked about the form that Idaho uses, noting that it does not indicate if information is sent to PCPs. Our hospitals are supposed to relay this information to PCPs, but there is no formal documentation that follows the child. It would be nice to have that documentation instead of relying on parent report. The Law and the Rule state that the hospital has to report to the state. Dr. Bohning noted that it is documented in the discharge summary at the University of Utah Hospital. In Utah, State EHDI results are sent electronically, not in hard copy, so doctors in the community are not necessarily getting that information. Nita will add this item to the next meeting's agenda. Completing a hard copy form on every baby may be quite time consuming. It is a matter of time and money to do all of these things.

If medical homes are not yet getting this information, they will have access to it eventually either through CHARM or the cHIE. There is still an ongoing project that will be putting all newborn screening data on the cHIE within the next year. Our project is to make the information available to the cHIE, but medical facilities will be responsible to get connected from the cHIE to their EMR. Meaningful use incentives have paid a lot of providers (who see Medicaid patients) to help get them connected. This will trickle down until Intermountain Healthcare and the University of Utah systems get on board.

NCHAM Activities

Dr. White discussed a proposed NCHAM physician survey in our last meeting. This is scheduled to be distributed later this month. Dr. Sharon Strong would like to get permission from the Academy of Family Physicians to use their mailing list to distribute information from this committee without having to seek prior approval every time. Dr. White noted another issue with pediatrician mailing lists is that, while we can obtain mailing addresses, they will not share email addresses. He would like to know if there is another way around this as he would like to give the option to respond to this survey by email. Our last mailing put out to the AAP mailing list was also distributed electronically by the AAP, so maybe email is still a possibility. Dr. White will speak with Cathy Oyler (AAP of Utah's secretary). Utah AAP may be able to include the survey in their regular newsletter. Diane Behl will also speak with Dr. Albert Park about getting addresses/email addresses for ENT providers.

NCHAM (in coordination with USDB) has received a grant to evaluate early intervention services for deaf/hard of hearing children utilizing tele-intervention. This would use 2-way video conferencing to provide services to the child and family at home. Dr. White showed a video clip of a tele-intervention session. NCHAM has piloted tele-intervention sessions with five families from Sound Beginnings. This grant will enable testing with a larger number of families. Their hope is to use tele-intervention with 30 children/families along with a matched comparison group of 30 families using face-to-face intervention. Half of the case load would use tele-intervention and half would have face-to-face intervention in order to compare if the tele-intervention setting is as effectual. They will collect data for cost, child outcomes, parent satisfaction and interaction. The hypothesis is that tele-intervention is better in a few ways than face-to-face intervention.

The first point to look at is the yield; if you look at scheduled home visits to families, most are only able to make it to half or 2/3 of their scheduled visits. For the five families piloted, the evidence of yield is higher for

meeting those scheduled services. The 2nd aspect in home intervention is that families will incorporate the various activities into their daily routines. One challenge in intervention is getting the parent to do things as many want the expert to do it; when they are on opposite sides of the camera, they have to do it and become more involved. The 3rd aspect is that all of the sessions are taped and put on a secure site so that mom can show dad what they did and how to do it. And if they don't understand something they are doing, they can review the videotape. The goal of this project would be to evaluate all three aspects.

Providers willing to provide tele-intervention will be identified and matched to families. The assumption is that tele-intervention will be cheaper, but there are a lot of costs associated with it and no one (nationwide) has collected this kind of data yet. Just having a tech to keep things running is very important and expensive, the equipment is expensive as well (they are just using Skype now). There are many unknowns, but they are hoping to kick this off in September. This would run for a year. This first pilot will take children statewide, but will be limited to families who have chosen LSL, as this is a larger group. They would also like the first test session to be in the family's native language so that will limit ASL and Spanish speaking families until they decide if the project is going to work. There are too many variables with those groups right now. They may have to branch out to other states if they cannot get 60 families within Utah. NCHAM will have data to report back in 6 months.

Family to Family Support

AG Bell held their annual Speech Fair in March. This was a good opportunity for parents to see the evolution of older children with hearing loss (preschoolers and up) and how they have progressed.

Taunya's son, Jaden Paxton, contacted a representative of Cochlear about sponsoring his scout troop on a bike ride from Pleasant Grove to Lake Powell. Cochlear has donated t-shirts for the ride and will receive increased awareness for their donation. For more details on the Paxton's journey go to achancetohear.com.

Guide by Your Side (GBYS) was discussed at the last meeting; this will be discussed again at the next meeting in August. The new local Hands and Voices (H&V) group seems to be pretty active. The previous discussion with H&V regarding GBYS was about their need for funding and what we could offer. Dr. White mentioned that it is a hard time for funding issues right now. He thinks everyone here is committed to the concept of family support in some form and that this is a discussion that is worth pursuing. He is not lobbying for H&V particularly, but we should take advantage of existing support networks and build on that. Taunya has heard from some people of unpleasant experiences with H&V because they did not feel that they were as unbiased as their mission statement. Taunya's first contact with H&V was not the best either. She believes that AG Bell is pretty straight forward about what they do and groups should be what they say they are. As a task force, we have the responsibility to make sure that families get respect and support for their choice. Dr. Harward agrees and thinks it is important to know that there are biases out there. When the topic of GBYS was recently raised, we thought we might have funding to use for this, but with recent cuts this may not be possible. Nita noted that in the past we have offered AG Bell assistance by helping with mailings, we could also offer this to H&V or just wait to see if they contact Dr. McVicar again. Other states have gone to the legislature to ask for funding to better support families in an unbiased manner and have succeeded in getting that funding. Dr. White feels that it would make an incredible difference if there were a family support group who could pursue this, and he can even put such a group in touch with those states that have been successful.

Lori Ruth feels like this family support is already happening with the PIP program and available funding could be better spent on things like bone conduction hearing aids. She suggested saving funding to help provide for these children. Dr. White is all in favor for bone conduction hearing aids and he is not pushing GBYS necessarily, but parent support in general. Minnesota and Indiana were able to get money to hire a full time

coordinator to get those supports. What Dr. White is hearing is that we don't have family to family support unless it is on a volunteer basis, not something structured, but he also has not done an investigation. USDB does have Saturday gatherings for families to come together and Lori always makes sure her families are comfortable and have someone that they can talk to. She thinks there are a lot of opportunities out there and we need to support what we already have, families just don't seem to take advantage of current opportunities. Maybe it is just a matter of awareness and promotion. Dr. Karen Munoz also wonders if issues are more location-based: these events are happening in Ogden, Orem, and Salt Lake, but they don't have anything further south. It might just be a matter of format. There is also a difference between having activities and having systematic outreach. Taunya's son Chance had a late diagnosis, and did not meet the Early Intervention service age, and they had to search out AG Bell. Dr. White believes that the ideal would be that when a child is diagnosed, no matter the age, there was a systematic family to family outreach that is unbiased and respectful. There are informal networks working, but many are biased. Again, he mentioned that Minnesota and Indiana have paid and trained people who systematically provide outreach whenever a child is identified with hearing loss, but that takes money. The position in Minnesota is handled through the State EHDI program. In Indiana it was done through the School for the Deaf, but that is shifting now. Taunya mentioned that with AG Bell, it is always the same people that are willing to be involved, everyone wants certain things but they don't want to put forth the effort. Dr. Dick said it would be worthwhile to get information from Dr. White as to what other states have done and report back on their structure, funding, how they are objective in providing that information and how they link with the Schools for the Deaf and PIP. What Minnesota experienced was family burn out, they were willing to do it for a while on their own but then get overwhelmed. One of the goals of MCHB is that families are part of the system and having them involved in service provision should be valued by paying for their time just like everyone else. That is how you get the sustainability. Volunteerism is wonderful, but it does send a message when you say "we really want you involved, but..." Rich would like to know the funding mechanisms that these states are using. Taunya and Dr. White will investigate this and report at the next meeting.

Lori brought the conversation back to the Newborn Hearing Standard Guidelines. She thinks 2 weeks for the referral to PIP is way too long, it should be done sooner. Dr. Harward stated that we are working on changing this timeline. Sometimes the referral has been made within the time frame, but it is not reported to the state EHDI program that quickly. These guidelines are distributed to the hospitals screening coordinators and state audiologists as part of their booklet of guidelines. Dr. Strong mentioned that it would be helpful if something showing actual statistics, like an efficiency report, would accompany the guidelines as well as one sentence that states why this is important and how we are currently doing. This would be a good opportunity to send out a letter saying that the guidelines have been revised for 2011, here are the averages and here is where we want to be. For now, we will send out the revised Standards (not efficiency reports) to hospital CEOs, screeners, and Audiologists. Sylvia would also like a list of Early Intervention providers sent out. Nita will include that list to the hearing screening coordinators. The revised list of pediatric audiologists will also be included in this mailing (to everyone).

Next meeting will be held August 14, 2012.

Adjourned by Dr. Dick at 11:10, vote to adjourn Karl White, Sylvia White.

Advisory meeting schedule for 2012: *August 14, November 13, 2012.* All meetings will be held from 9-11am at the Utah Dept of Health, CSHCN Building , 44 Mario Capecchi Dr, SLC, Conference Rooms C-D.

Mark your calendars for the 2013 meetings: February 12, May 14, August 13, and November 12.

FYI –You may subscribe to notices regarding this Committee on the Utah Public Notice website with instructions at <http://pmn.utah.gov> . Agendas will also be posted on that website at least 24 hours prior to the scheduled meeting.